

## 10 Things to know about the RMS Investigation

### 1. What is the NH Cancer Registry?

The New Hampshire State Cancer Registry (NHSCR) is a statewide, population-based cancer surveillance program that collects incidence data on all cancer cases diagnosed or treated in the State of New Hampshire. Through interstate agreements, information on New Hampshire residents diagnosed or treated in other states (i.e., Massachusetts, Maine, Vermont, Connecticut, New York, New Jersey, and Florida) is also reported to the NHSCR to be included in the registry. The state cancer registry typically does not collect information directly from patients. Established in 1985, the NHSCR is a partnership between Geisel Medical School at Dartmouth and the NH Division of Public Health Services. The NHSCR is part of a statewide effort to reduce the impact of cancer on individuals, families and communities in New Hampshire.

The New Hampshire State Cancer Registry:

1. Maintains an incidence reporting system for the estimation of cancer rates in NH
2. Provides information to help public health officials and agencies in the planning and evaluation of cancer prevention and control programs, and in cancer cluster investigations
3. Acts as an informational resource for investigation of cancer and its causes

New Hampshire State law requires New Hampshire physicians and hospitals to report to the NHSCR all cases of cancer and benign brain tumors that are diagnosed or treated, within six months of diagnosis. In practice, it sometimes takes longer than six months for the registry to receive reports on some cases.

The Centers for Disease Control and Prevention provides support for states and territories to maintain cancer registries that provide high-quality data. This data enables public health professionals to more effectively understand and address the cancer burden.

For more information:

<http://www.dhhs.nh.gov/dphs/hsdm/cancer/>

<http://geiselmed.dartmouth.edu/nhscr/about/>

<http://www.cdc.gov/cancer/npcr/>

## 2. What is a cancer cluster?

CDC defines a cancer cluster as *a greater than expected number of cancer cases that occurs within a group of people in a geographic area over a defined period of time*. This definition can be broken down as follows:

- *“a greater than expected number”*: To determine whether the number of observed cancer cases is greater than would normally be observed (or expected) a comparison is made to the incidence of cancer in a similar community (e.g., a comparison population of similar size and demographics).
- *“of cancer cases”*: The cancer cases are all of the same type. In rare situations, multiple cancer types can be considered when a known exposure (e.g., radiation or a specific chemical) is linked to more than one cancer type or when more than one contaminant or exposure type has been identified.
- *“that occurs within a group of people”*: The population in which the cancer cases are occurring is defined by its demographic factors (e.g., race/ethnicity, age, and sex).
- *“in a geographic area”*: The geographic boundaries used for determining which cancer cases to include in the calculation of the expected rate of cancer diagnoses are defined carefully. It is possible to "create" or "obscure" a cluster accidentally by selection of a specific area.
- *“over a period of time”*: The time period chosen for analysis will affect both the total cases observed and the calculation of the expected incidence of cancer in the population.

More information about defining a cancer cluster can be found at:

<http://www.cdc.gov/mmwr/preview/mmwrhtml/rr6208a1.htm>

## 3. What is the role of Public Health after a cancer cluster is suspected?

The role of the New Hampshire Department of Health and Human Services, Division of Public Health Services (DPHS), is to respond to the health concerns of the community. In response to concerns about a possible cancer cluster, DPHS seeks to identify whether an environmental exposure may be present in the community that is leading to cancer development and to prevent, if possible, development of future cancers. This response involves a series of steps and ongoing communication with the community to inform efforts.

### Step1:

The first step after we receive a report about concern for a cluster of cancer cases within a New Hampshire community is to gather additional information from concerned individuals about the type(s) and numbers of cancers involved; any suspected exposure(s) that might cause cancer, the area and time period in which the case(s) occurred, information about the persons affected, and specific information about the cancers themselves. Following review of this information a determination is made about the need for further investigation, taking into consideration factors that would make a cancer cluster unlikely (e.g., cancer cases within family members, different types of cancer, a few cases of a very common cancer, cases involving people who don't have a common geographic exposure).

### **Step 2:**

If DPHS determines that the possibility for a cancer cluster exists and should be studied further, additional steps are taken:

- The reported cancer cases are confirmed in the NHSCR.
- Information about potential environmental exposures is gathered from the community and other government agencies.
- A review of the scientific literature is performed to identify known environmental or behavioral factors that have been associated with development of the cancer of concern.
- The NHSCR data is used to assess whether the observed number of the specific type of cancer reported in the registry is greater than what would be expected when compared to a similar population for a defined period of time and within a defined geographic area (see cancer cluster definition above). Standard statistical methods are used to evaluate the significance of any differences that are found. These statistics help determine whether further investigation is necessary, feasible, and likely to identify a cause of a cancer cluster.

This initial analysis described above is a population-level evaluation of cancer rates based on NHSCR data and does not collect personal or medical record level information.

### **Step 3**

The feasibility of conducting an epidemiological study to examine association(s) between the cancer of concern and environmental exposures is assessed. Specifically, a study hypothesis is made and a case definition is developed to focus further investigation on specific cancer(s) that

are found in higher numbers than expected. An evaluation is also made regarding the possibility that local environmental exposure(s) may have led to cancer development. Finally, DPHS develops a study design and identifies resources needed to complete the investigation.

#### **Step 4**

If the activities outlined in Step 3 suggest that further study is warranted, an epidemiologic investigation of the suspected cancer cluster is performed to determine if the cancer under investigation is associated with exposure to a specific risk factor or environmental contaminant.

Community members should be aware that these types of epidemiological investigations are difficult and rarely identify causes for cancer development.

#### **4. How common is cancer?**

Cancer is not just one single disease but many, each associated with a specific set of possible causes that may relate to a person's genetic make-up, personal behaviors (e.g., diet, inactivity, smoking and alcohol consumption) and the environment (e.g., radon, arsenic, exposure to secondhand smoke). Cancer diagnoses are becoming increasingly common; as people continue to live longer their risk for cancer increases. Additionally, improvements in cancer treatments have led people to live longer after a cancer diagnosis, which in turn means that the number of people in a community who have experienced cancer is higher than it was before these advances in medical care.

Pediatric cancers make up about 1% of all cancers diagnosed each year. According to the American Cancer Society an estimated 10,450 new cases occur annually in the United States. Each year in New Hampshire about 46 children are diagnosed with cancer and five children die due to cancer. Unlike many cancers in adults, the specific causes of cancer in children are largely unknown (80-90%). It is estimated that 10-15% of childhood cancer cases may be attributed solely to genetic and familial factors, and only 5-10% or less may be linked to environmental risk factors.

Sources:

<https://www.nh.gov/epht/publications/documents/nhchildrenreport.pdf>

<http://www.dhhs.nh.gov/dphs/hsdm/cancer/documents/rhabdomyosarcoma2016.pdf>

Many people believe that cancer is usually caused by exposure to toxic substances, but toxins in the environment account for a relatively small percentage of all cancer deaths. Most geographic differences in cancer rates seem to result more from differences in lifestyle rather than from anything in the physical surroundings. Almost two-thirds of cancer deaths in the United States may be linked to tobacco use, adult diet, obesity and lack of exercise. By contrast, only an estimated four percent of all cancer deaths can be attributed to environmental pollution or radiation.

However, occupational studies have shown that certain chemicals can be carcinogenic (i.e. cause cancer); these include asbestos, benzene, arsenic, vinyl chloride and other industrial products. Occupational exposures are thought to account for about four percent of cancer deaths. An estimated 10 percent of lung cancer cases are due to radon exposure, and the risk is higher among people who also smoke tobacco. Unfortunately, less is known about the causes of rarer cancers because it is much more difficult to conduct meaningful research when a disease is rare.

[http://healthvermont.gov/prevent/cancer/monitor\\_cancer.aspx](http://healthvermont.gov/prevent/cancer/monitor_cancer.aspx)

## **5. What is RMS?**

Rhabdomyosarcoma (RMS) is a rare type of soft tissue cancer (sarcoma) that resembles bone and muscle and arises from early developmental skeletal muscle cells. It is the most common soft tissue tumor of childhood and represents about 3-4% of all childhood cancers. Two-thirds of cases are diagnosed in children under the age of six, and more boys are affected than girls. The incidence rate of RMS in children under 20 years of age is approximately 4.3 cases per million per year, and about 350 new cases of RMS occur each year in the United States. RMS can arise anywhere in the body and the common sites are head and neck, genitourinary tract, and the extremities.

Most cases of RMS appear to be random without any clearly identifiable cause, but there do appear to be connections between RMS and different familial (inherited) conditions and specific genetic mutations. Up to one-third of children with soft tissue sarcomas may have a genetic predisposition.

No definite environmental exposures or behavioral risk factors for RMS have been identified. A number of small studies have evaluated parental exposures and habits, and the prenatal environment, without any consistent or clearly identified risk factors. Our understanding of the causes of RMS is limited because it is a rare cancer, and more difficult to study.

<http://www.dhhs.nh.gov/dphs/hsdm/cancer/documents/rhabdomyosarcoma2016.pdf>

#### **6. Was there a greater than expected number of RMS cancers in Rye?**

The incidence of RMS in all of New Hampshire is similar to that of the U.S. white population. During the 10 years from 2005-2014, there were 14 total cases of pediatric RMS among New Hampshire residents; fewer than 5 cases were in the five-town area that included Rye and the neighboring four towns of Newcastle, Portsmouth, Greenland, and North Hampton. For confidentiality reasons, we cannot report the exact number of cases if it is fewer than five.

The number of pediatric RMS cases in the five-town area, was greater than expected when compared with the rest of Rockingham County or the state of New Hampshire. The small number of RMS cases over the 10-year time period, however, makes it difficult to know what the findings mean. For more information about the findings of the investigation of RMS cases in the Rye area, please review the report at:

<http://www.dhhs.nh.gov/dphs/hsdm/cancer/documents/rhabdomyosarcoma2016.pdf>

#### **7. Are there other pediatric cancer cases in the Rye area, and were these investigated?**

From 2005-2014, there were a total of 18 pediatric cancer cases reported to the NHSCR. Additional analyses were performed to evaluate the more commonly identified cancers in the five-town area of Rye, Newcastle, Portsmouth, Greenland, and North Hampton. The additional cancers analyzed included leukemia, brain and other central nervous system cancers, and lymphoma, in addition to lung and bronchus cancer, which is relatively rare in children, but a small number of cases were noted. The total numbers of reported pediatric cancer cases for each subtype were small, with mostly fewer than 5 cases depending on the type of cancer. Most analyses did not reveal a statistically significant greater than expected number of cancer

cases, with the exception of a cancer called pleuropulmonary blastoma (PPB), which has a strong genetic or familial etiology that is described further in our report.

<http://www.dhhs.nh.gov/dphs/hsdm/cancer/documents/rhabdomyosarcoma2016.pdf>

#### **8. Did the State Cancer Registry identify all the pediatric cancer cases that have occurred in the seacoast region?**

During the community meeting in Rye on March 15, 2016 concerns were expressed that cases of childhood RMS had been missed and were not included in the report. Cancers were included in our report if they occurred in residents of the 5-town area that was evaluated.

If a child moves to a different state before diagnosis, they would not be included in our analysis because they are not reported to the NHSCR. Similarly, the NHSCR would not receive information on an RMS case if the child's state of residence (as provided to the hospital) is not New Hampshire. For example, if a family moves temporarily for treatment to a different state, the case may be registered to that state, rather than to NH. Because many pediatric cancers are treated in Massachusetts, we depend on our inter-state information exchange agreements to receive complete data for New Hampshire residents treated outside the state.

We have checked all of the information provided to us by community members about specific pediatric cancer cases, and we have confirmed that all of the cases reported to us were recorded in the cancer registry. Therefore, the published report on RMS and other pediatric cancers counts all individuals that that it should. Due to the possibility, however, that individuals may have lived in the seacoast area but switched residence to another state at the time of RMS cancer diagnosis, we will be broadening our investigation to identify additional individuals that may have a connection to the seacoast area to include them in further investigation.

#### **9. What do I do if I know about individuals with RMS who are not residents of NH, but have a connection to the Seacoast area?**

If you have information about an individual diagnosed with RMS who has a connection with the seacoast area, please fill out the following survey and someone from the NH DPHS will be in contact with you: <https://www.surveymonkey.com/r/RMSInfo>

**10. Is the information in the NH State Cancer Registry kept confidential?**

Yes. The identities of individual cancer patients, physicians and facilities are protected by law and there are strict measures taken to protect the confidentiality of patients and prevent public disclosure. These measures include not publically reporting the number of cases in a small geographic area, when that number is small. The reason for this is that even tiny pieces of information can sometimes be used together to identify individuals, and we have a duty to protect individuals from that invasion of privacy.

The New Hampshire Administrative Rules that describe cancer reporting expectations and protections for confidentiality can under He-P 304 Cancer Registry Rules ([http://www.gencourt.state.nh.us/rules/state\\_agencies/he-p300.html](http://www.gencourt.state.nh.us/rules/state_agencies/he-p300.html)).